Complete Summary

GUIDELINE TITLE

Preventive health recommendations for adults with mental retardation.

BIBLIOGRAPHIC SOURCE(S)

Massachusetts Department of Mental Retardation, Univ of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research. Preventive health recommendations for adults with mental retardation. Boston (MA): Massachusetts Department of Mental Retardation and University of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research; 2003 Sep 19. 2 p.

COMPLETE SUMMARY CONTENT

SCOPE

DISEASE/CONDITION(S)

- Mental retardation
- Cancer (breast, cervical, colorectal, testicular, prostate, and skin)
- Infectious diseases (chlamydia, sexually transmitted diseases, human immunodeficiency virus [HIV], hepatitis B and C, tuberculosis, influenza, pneumonia)
- Hypertension
- Cholesterolemia
- Diabetes
- Osteoporosis
- Hearing and vision impairments
- Glaucoma
- Depression
- Dementia

GUIDELINE CATEGORY

Prevention
Screening

CLINICAL SPECIALTY

Family Practice
Internal Medicine
Preventive Medicine

INTENDED USERS

Health Care Providers
Physician Assistants
Physicians

GUIDELINE OBJECTIVE(S)

To present preventive health recommendations for adults with mental retardation

TARGET POPULATION

Adults with mental retardation

INTERVENTIONS AND PRACTICES CONSIDERED

Specific preventive health interventions and practices for the Department of Mental Retardation-mandated annual physical exam:

Screening

Cancer Screening

1. Clinical and self breast examination
2. Mammography
3. Clinical and self testicular examination
4. Pap smear
5. Fecal occult blood testing
6. Skin examination

Infectious Disease Screening

Chlamydia, sexually transmitted disease, human immunodeficiency virus [HIV], hepatitis B and C, tuberculosis testing

Sensory Screening

Hearing and vision testing

Mental and Behavioral Health Screening

Depression and dementia assessments

Other Screening

1. Thyroid function test
2. Cervical spine x-ray
3. Echocardiogram
4. Hypertension testing
5. Cholesterol testing
6. Diabetes (Type II) testing
7. Liver function testing
8. Osteoporosis testing

Prevention

1. Immunization for influenza, pneumococcus, hepatitis B
2. General counseling and guidance

MAJOR OUTCOMES CONSIDERED

Not stated

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Comprehensive review of available Medline/PubMed sources, materials developed by advocacy and state agencies.

NUMBER OF SOURCE DOCUMENTS

16 documents used by the expert panel

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus (Committee)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

METHODS USED TO ANALYZE THE EVIDENCE

Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

The development of the recommendations required careful consideration of many elements in the lives of adults with mental retardation.

Phase I

Committee members received a package of reference material for review prior to the initial meeting. Members reviewed the general findings from the literature search and discussed their own professional experience in community care for people with mental retardation. Following discussion, committee members agreed to adopt generally accepted Massachusetts Health Quality Partners (MHQP) guidelines for the general population as a baseline and develop recommendations for modifications to address areas of greater concern for the population of people with mental retardation.

Based on findings in the literature and the experience of committee members, three focus areas emerged:

1. The need to review and modify generic MHQP standards to ensure they are appropriate to the health needs of the adult population with mental retardation.
2. The need to facilitate effective communication relating to an individual's health, lifestyle, adaptive functioning, and service plan between residential staff or family members and the community clinician.
3. The need to consider additional recommendations for sub-populations such as those with identifiable syndromes or comorbid conditions that are associated with additional health risks.

The committee formed three sub-groups and each group was charged with developing recommendations to address one of the above areas.

Phase II

Subcommittees met to develop recommendations that were shared at a second Advisory Committee meeting. The entire Advisory Committee reviewed and commented on the work of each subcommittee. The subcommittees then formed their final recommendations.

Phase III

The final meeting and discussion of the Advisory Committee was held for discussion of the remaining work of each committee. Subcommittee members agreed to complete recommendations for the final report to be forwarded to the Department of Mental of Retardation.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Not stated

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Note: Items that are indicated in bold italic are specific recommendations that differ from the Massachusetts Health Quality Partners (MHQP) recommendations in order to reflect particular health concerns of the population with mental retardation.

Health Maintenance Visit, including height and weight measurement

- 19-29 years: annually
- 30-39 years: annually
- 40-49 years: annually
- 50-64 years: annually
- 65+ years: annually

Breast Cancer: Mammography

- 19-39 years: Clinical breast exam and self-exam and self-exam instruction as appropriate. Mammography not routine except for patients at high risk. Accurate and detailed history and family history will identify risk factors.
- 40-49 years: Clinical breast exam and self-exam instruction as appropriate. Mammography every 1 to 2 years, at discretion of physician.
- 50-64 years: Clinical breast exam and self-exam instruction as appropriate. Annual mammography
- 65+ years: Mammography annually through age 69 years. Age 70 years and older, annually at the discretion of the physician.

Cervical Cancer: Pap Smear

- 19-64 years: Every 1 to 3 years, at physician's discretion
- 65+ years: May be omitted after age 65 if previous screenings were consistently normal

Colorectal Cancer

- 19-49 years: Not routine except for patients at high risk
- 50-65+ years: Fecal Occult Blood testing annually and sigmoidoscopy every 5 years OR colonoscopy every 10 years

Testicular and Prostate Cancer

- 19-39 years: Clinical testicular exam and self-exam instruction as appropriate. Prostate cancer screening not routine.
- 40-49 years: Not routine except for patients at high risk. Risk factors include: family history and African-American ancestry.
- 50-65+ years: At physician discretion after discussion of risks and benefits of available screening strategies (prostate specific antigen [PSA], digital rectal examination [DRE]).

Skin Cancer

- 19-65+ years: Periodic total skin exams targeting populations at high risk for malignant melanomas. Frequency at physician discretion.

Hypertension

- 19-65+ years: At least annually

Cholesterol

- 19-64 years: Every five years or at physician discretion
- 65+ years: at physician discretion

Diabetes (Type II)

- 19-65+ years: At least every 5 years until age 45. Every 3 years after age 45. Fasting plasma glucose screen for individuals at high risk. Risk factors include: family history of premature coronary heart disease (CHD), hypertension, diabetes mellitus, peripheral atherosclerosis or carotid artery disease, current cigarette smoking, or high-density lipoprotein (HDL) >35 mg/dL.

Liver Function

- 19-65+ years: Annually for hepatitis B carriers. At physician discretion after consideration of risk factors including long term prescription medication

Osteoporosis

- 19-64 years: Bone density screening when risk factors are present: long term polypharmacy, mobility impairments, hypothyroid, post-menopausal women. Periodicity of screening at physician discretion. Annually counsel about preventive measures including dietary calcium and vitamin D intake, weight-bearing exercise, and smoking cessation.
- 65+ years: Counsel elderly patients about specific measures to prevent falls.

Chlamydia and Sexually Transmitted Diseases (STDs)

- 19-29 years: For all sexually active males and females screen annually <25 years. >25 years screen annually if at risk.
- 30-65+ years: Annually if at risk. Risk factors include inconsistent use of barrier contraceptives, new or multiple sex partners in last 3 months, a new partner since last test, a history of STD, infected with another STD, and partner has had other sexual partner(s).

Human Immunodeficiency Virus (HIV)

- 19-65+ years: Periodic testing if at risk and testing of pregnant women at increased risk

Hepatitis B and C

- 19-65+ years: Periodic testing if risk factors present

Tuberculosis

- 19-65+ years: Tuberculin skin testing every 1 to 2 years when risk factors present. Risk factors include residents or employees of congregate setting, close contact with persons known or suspected to have tuberculosis (TB).

Hearing assessment

- 19-65+ years: Screen annually. Re-evaluate if hearing problem is reported or a change in behavior is noted.

Vision assessment

- 19-65+ years: Screen annually. Re-evaluate if vision problems are reported or a change in behavior is noted.

Eye Exam for Glaucoma

- 19-39 years: Every 3 to 5 years in high risk patients. At least once in patients with no risk factors.
- 40-64 years: every 2 to 4 years
- 65+ years: every 1 to 2 years

Depression

- 19-65+ years: Screen annually for sleep, appetite disturbance, weight loss, general agitation.

Dementia

- 19-39 years: Monitor for problems performing daily activities.
- 40-65+ years: In persons with Down Syndrome, annual screen after age 40.

Immunizations (as for the general adult population with the following exceptions)

1. Influenza vaccine
   19-65+ years: Annually
2. Pneumococcal vaccine
   19-65+ years: Once
3. Hepatitis B vaccine
   19-65+ years: Once. Reevaluate antibody status every 5 years.

For persons with Down Syndrome (in addition to the above recommendations)

1. Thyroid function test
   19-65+ years: Every 3 years (sensitive thyroid stimulating hormone [TSH])
2. Cervical spine x-ray to rule out atlanto-axial instability
   19-65+ years: Obtain baseline as adult. Recommend repeat if symptomatic, or 30 years from baseline.
3. Echocardiogram
   19-65+ years: Obtain baseline if no records of cardiac function are available.

General counseling and guidance

1. Prevention counseling
   19-65+ years: Annually counsel regarding prevention of accidents related to falls, fire/burns, choking.
2. Abuse or neglect
   19-65+ years: Annually monitor for behavioral signs of abuse and neglect.
3. Preconception counseling
   19-65+ years: As appropriate, including genetic counseling, folic acid supplementation, discussion of parenting capability.
4. Healthy lifestyle
   19-65+ years: Annually counsel regarding diet/nutrition, incorporating regular physical activity into daily routines, substance abuse.

<u>General Counseling and Guidance Recommendations</u>

Injury Prevention & Safety: Annually counsel caregivers to be alert to ways to prevent household injuries (fall prevention, choking prevention, fire/burn prevention).

Family Violence/Abuse: On all visits be alert to physical and behavioral signs and symptoms associated with abuse and neglect. Routinely ask all patients direct, specific questions about abuse including sexual abuse.

Preconception Counseling: Preconceptual counseling should include genetic counseling for hereditable conditions, assessment and discussion of parenting capability, as well as folic acid supplementation.

Menopause Management: Ages 40 – 50. Be alert to signs and symptoms of menopause; consider appropriate therapies to control symptoms.

Other testing considerations when individual has limited communication capacity.
For individuals who have significantly limited means of communicating their symptoms, screening labs (blood chemistries, complete blood count [CBC], perhaps TSH) should be considered at each annual health maintenance visit in order to supplement available information. Alternatively, in order to prevent unnecessary follow-up evaluations, it may be preferable to limit testing to the evaluation of specifically identified problems when a thorough and detailed history can be obtained from familiar caregivers.

Preparation for an examination

Many adults can be helped to feel more comfortable at a medical visit if they feel adequately prepared for the event. Family or support staff can be encouraged to introduce unfamiliar items such as a stethoscope or a blood pressure cuff at home to allow the instrument to become more familiar and facilitate cooperation during an exam.

During the exam, it is helpful to prepare patients for procedures by explaining them well or allowing patients with sensory impairments to explore the instruments that are about to be used. Performing simple examinations in an office or quiet waiting room may reduce a person's anxiety.

If someone is particularly anxious or an invasive screening procedure is necessary, the clinician might consider sedation prior to the appointment. In some cases, multiple procedures can be performed while the patient is sedated (dental work, or routine blood work, for example) to reduce the number of times a person is exposed to the risks of sedation.

Refer to Attachment D of the companion document "Preventive Health Standards Project FINAL REPORT," Center for Developmental Disabilities Evaluation and Research.

Communication

If a patient is unable to communicate regarding his or her own health status, clinicians may have to rely on a family member or support staff to provide information relating to signs or symptoms of health concerns. Questions regarding changes in the individual's behavior and adaptive function can bring underlying physical and mental health issues to light.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The recommendations are based on the Massachusetts Health Quality Partnership (MHQP) Adult Preventive Care Recommendations 2003.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Appropriate preventive healthcare for adults with mental retardation

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

With the presentation of these recommendations, the Advisory Committee does not intend to imply that adults with mental retardation all have similar health needs or that clinicians should not continue to use their clinical judgment and seek additional consultation when necessary. The Advisory Committee sees these recommendations as one of a number of steps towards ensuring that every adult with mental retardation receives the most appropriate health care as an individual.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

Massachusetts Department of Mental Retardation had included prompts for preventive health screening as a required element in their residential provider systems. Recommendations pamphlet mailed to all general and family practitioners in the Commonwealth.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Living with Illness
Staying Healthy

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Massachusetts Department of Mental Retardation, Univ of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research. Preventive health recommendations for adults with mental retardation. Boston (MA): Massachusetts Department of Mental Retardation and University of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research; 2003 Sep 19. 2 p.

ADAPTATION

The recommendations are based on the Massachusetts Health Quality Partners (MHQP) Adult Preventive Care Recommendations 2003.

DATE RELEASED

2003 Sep 19

GUIDELINE DEVELOPER(S)

Massachusetts Department of Mental Retardation - State/Local Government Agency [U.S.]
University of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research - Academic Institution

SOURCE(S) OF FUNDING

Massachusetts Department of Mental Retardation

GUIDELINE COMMITTEE

Massachusetts Department of Mental Retardation Preventive Health Standards Advisory Committee

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

Committee members: Victor Acquista, MD; Norberto Alvarez, MD; Bob Baldor, MD; Allen Crocker, MD; Marc Emmerich, MD; Warren Ferguson, MD; Jim Gleason, PT; Adria Hodas, RN NP; Elizabeth King, RN NP; Leo McKenna, PharmD.; Barbara

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Print copies: Available from the University of Massachusetts Medical School, Center for Developmental Disabilities Evaluation and Research, 200 Trapelo Road, Waltham, MA 02452; Phone: (781) 642-0283; Fax: (781) 642-0162.

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- Preventive health recommendations for adults with mental retardation. Guidelines for community practitioners. Boston (MA): Massachusetts Department of Mental Retardation and University of Massachusetts Medical School Center for Development Disabilities Evaluation and Research; 2002 (revised 2003 Sep). 2 p.
- Preventive health standards project. Final report. Center for Developmental Disabilities Evaluation and Research; 2002 (revised 2003 Apr 11). 54 p.

Print copies: Available from the University of Massachusetts Medical School, Center for Developmental Disabilities Evaluation and Research, 200 Trapelo Road, Waltham, MA 02452; Phone: (781) 642-0283; Fax: (781) 642-0162.

PATIENT RESOURCES

None available

NGC STATUS

This summary was prepared by ECRI on January 29, 2004. The information was verified by the guideline developer on February 26, 2004.

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